THE POWER OF POSITIVE LINKING:

How families can empower people who have a mental handicap through mutual support groups

The G. Allan Roeher Institute

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FOREWORD

As community life becomes a more tangible reality for people with mental handicaps, the many faces of the movement for community living are beginning to emerge. Self-advocacy groups, organizations providing community services, and new organizations advocating on behalf of people who have been labelled in our society are quickly growing in number and range. Informal, mutual support groups of families and friends of people with handicaps are also emerging in all corners of the country, sharing their commitment and vision for community living and helping the movement to rediscover its own roots. As all these groups evolve, they seek ways in which their unique roles in the movement can be valued and supported.

This study is about the experience and practice of five informal, mutual support groups in Canada. Their experience provides concrete evidence of empowerment and strategies for getting there. It tracks the development of such groups in their attempts to build personal relationships of trust and commitment, to develop individual strengths and initiative. It looks at how the groups form, what makes them stay together, and in particular, the process they go through in pursuit of change. It describes the specific goals the groups seek. These vary among the groups and include securing and delivering services; finding a means through which to lobby government for change; creating a climate of friendship and support that helps to secure personal development and growth; and providing emotional support that encourages self-esteem and a sense of dignity.

The issues this study raises are important for several reasons. Many families in Canada are searching for ways to empower their family member with a mental handicap. Many would like to form self-help groups of their own. The study attempts to fill the gap by offering the experience of a few existing groups. Associations will find this experience of interest since personal growth and empowerment among community members ultimately affects the kinds of services and organizational structures these members will require. In this sense, the study encourages cooperation and dialogue between the various service and support associations, advocacy groups, and mutual support groups that make up the movement for community living.

Finally, this study makes clear that mutual support among families must be understood as part of the challenge to society offered by the community living movement. We have begun to learn that this challenge includes the closure of all institutions, the affirmation of human rights and equality for people with handicaps, and the development of community services that provide for dignity and quality of life. The experience of groups documented in this study suggests, however, that mutual support among families and friends of people with a handicap is another essential component of this process for social change. The vision, commitment, and shared resources these groups bring into the lives of families and individuals are foundations for making community living a concrete reality. As the experience of groups in this study makes clear, mutual support can also be a foundation for designing systems that give real decision-making power to those who lack it. Just as we are working as a movement to create a social and political will to secure equality and lives of dignity in the community for people with handicaps, we also need to turn our attention to creating an environment in which mutual support can grow. This is the message and the hope of *The Power of Positive Linking*.

The Institute would like to thank all those who contributed to *The Power of Positive Linking*. A special mention is due to the individual members of the family support groups who gave a great deal of their personal time to The Institute for this study. Their cooperation and commitment to community living has made such an endeavour possible. The Institute would also like to thank Andre Foks for his painting and Marlene Neto for her illustrations, which were loaned to us for this book. A special thanks also to Anne Pollett and the Metropolitan Toronto School Board for their support and cooperation in making it possible to use this art.

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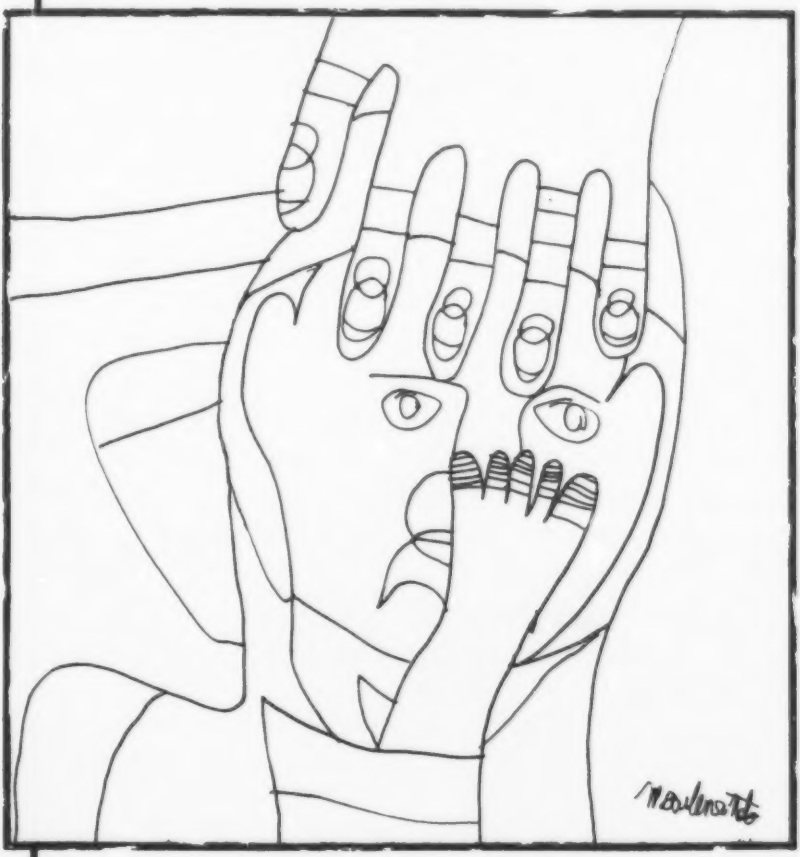


INTRODUCTION

"What is empowerment?
It is the process by which we can achieve
control over decisions that affect our lives.
It means gaining independence
through mutual support and cooperation,
encouragement and understanding.
It is the passing of power from one person to another.
The process of learning to shift power
to a person with a handicap and his or her family
is also one of empowerment.
It can be a difficult, even a threatening, one."

Decisions about where to live, get an education, work, recreate, and spend money are most often made by the agencies providing or funding services for a person with a handicap. These decisions are made with or without consultation from the person or the person's network. So, when a shift in power does take place, it is often achieved in a struggle that causes families and service providers to see each other as adversaries.

However, a more optimistic picture is possible. This study presents the process of empowerment as it is experienced by five groups of families in Canada. The study traces the process from the families' early feelings of being separate and powerless to later stages where a re-alignment of power has allowed for cooperation and interdependence.

From the many support groups across Canada, the five selected for this study were chosen according to a number of criteria. A guiding criterion was that groups were composed of personal networks — i.e., the friends, family, and others concerned about the person with a handicap. They are groups that have learned to act on behalf of the person, when needed or requested, and that have become one of the mechanisms to bring decision-making power closer to the individual using services. Among other criteria, it was important that each group have a vision to enhance the value and worth of people with a mental handicap, be independent from other existing association structures, provide members with emotional support, and have articulated a set of goals and strategies. The five groups represented in this study include: **The Abbie Lane 9 Group** in Halifax, Nova Scotia; **Parent Resources for Young Disabled (PRYD)** in Bathurst, New Brunswick; **Parent Link** in Toronto, Ontario; **The Calgary Community Living Society** in Calgary, Alberta; and **Family Link** in Vancouver, British Columbia. Several other groups were also visited for additional information.

Of the five groups involved in the research, three began when families came together to seek support in responding to a crisis in the life of a family member with a mental handicap. A combination of events brought the families together to form a group. In one instance, a proposed change in the institution's program of care necessitated the group's formation. In another, a mounting dissatisfaction among families and friends with the kind and quality of services being provided was the catalyst for their first meeting. The third group, while experiencing the same dissatisfaction, was inspired by one of the other groups in the study and formed to start alternative community services.

The fourth group in the study began as a very small, informal group of parents who wanted to increase opportunities for sons and daughters, all of whom were living at home. In so doing, they developed slowly and naturally into a self-help group whose goals had more to do with the growth and maturation of the members than the implementation of alternative services. Another similar group, for whom only preliminary interviews were carried out, also began with a few couples who needed to talk about what they were experiencing as parents of a child with a handicap. They have remained true to that purpose over the ensuing years. The members support each other emotionally both to solve problems and to celebrate victories. They also support each other by providing information and technical resources so that they can be more knowledgeable and informed as advocates.

The fifth group was formed to do both. The families set up services in response to a crisis, and provided family-to-family support on a personal level. On the one hand, this group actively supported families to have their young adult children move to community living from a nursing home and actually assisted in the setting up and operation of services. On the other hand, they continued to be with other families, one-to-one, or in small groups in a very personal

way, listening, advising, helping. This assistance took whatever form was needed: for example, bolstering a family's confidence, providing technical information, accompanying parents to stressful meetings, or providing space and refreshments for families to get together.

Information about the experience of these groups has been gathered through in-depth interviews with the families, friends, advocates, and group leaders involved, attendance at group meetings, and review of any relevant documents the groups provided. None of the groups is referred to by name in this study. Because the purpose was to provide an overview of the process of empowerment, the particular path of each group in this process has not been highlighted. Therefore, the quotes from interviews that appear in the text are used more to illuminate a general process of empowerment than to refer to the specific history of a particular group.

The study is organized into four sections that describe and reflect the experience of these groups. The first chapter examines how groups come together and how they establish a process for supporting each other. It also examines the kinds of goals that emerge from the mutual support they provide. The second chapter looks more closely at how the groups build their own strengths and capacities, the roles of members, their internal structure, leadership, and the means for resolving conflicts within the group. "Managing outside resources" is the theme of the third chapter. Groups begin their growth as an autonomous unit and later must develop strategies for interdependence with other organizations to get the resources they need to achieve their goals. Managing this transition is recognized as a critical step for support groups. The final chapter is a summary and overview of the stages through which groups pass as they develop the capacity to empower each other so as to pass that power on to a person with a handicap.

DEVELOPING MUTUAL SUPPORT

"We have unemployed, poor, uneducated people all
the way up to those
who own their own business.
We blend like soup and biscuits.
We all started out together,
we all come out together."

The support groups represented in this study were diverse in their composition. Although in all of them many more women than men were involved, in other ways the groups were composed of a range of individuals — both young people and old; mostly "middle-class," but all groups had members who were richer and some who were poorer. There were successful business people and also people in the group who rely on social security. As one woman said, members "go from black to white with all shades in between." People were quiet, strong, reserved. There were those who were vocal at meetings and those who were quiet, "but they are all part of it all."

These groups came together in spite of their individual differences. Their roots had very little to do with similarities of class, or race, or religion. Rather, their roots were found in four important characteristics: their ability to recognize each others' needs; their common experiences; their shared commitment to change; and the goals they developed for action. This chapter explores how mutual support developed between families and friends of people with a mental handicap.

Recognizing Needs

Some groups began because one person recognized a need and found other people to assist in filling it. For example, one parent needed to talk to other parents about the ups and downs of raising a child with a handicap. She phoned her doctor and asked to have other parents referred to her if they were willing. They began to meet as a group to share their experiences. Another mother saw her children needing friends and, with other parents, began a Day Camp. Other groups came together because they had been called to deal with a specific issue — the closure or the renovation of an institution, or the desire to provide community living for a family member. Sometimes, the comments from the groups reflected just how desperate the situation was for some families, so fundamental were the needs that they perceived:

"What kept us together was that we needed to ensure that our kids stayed alive and weren't abused."

One woman described the origins of her group in this way:

"The families who drew together were the ones with the higher needs. The families whose children function pretty well were not necessarily part of our group, although they are now. But the nugget [of families] that we had were all [those with] special, special needs. And that's what drew us together."

The same woman talked of how the need for services led to parents sharing their hopes and fears:

"We needed to find the other parents and sit down and find out what was needed. Because what was out there was crud! I didn't want [my children] to recreate alone or only with other disabled kids. We wanted them to get out and have friends ... The need for recreation grew into the need to ensure a better life ... and coming together to get activities and friendships grew into support amongst families and led to talking deeply to each other."

Although groups came together because of a recognition that some basic needs had to be met, people quickly went deeper, to examine the experiences that underlay those needs. In doing so, the roots of mutual support were discovered and strengthened.

Common Experience

Whatever the particular reasons that brought them together, most members passed through an intense emotional period: relief at discovering how much they have in common and that finally they have a place to be heard; joy at finding others who see value and worth in a son or daughter; and feelings, too, of anger and frustration or sorrow because they feel powerless to influence or change what concerned them in the lives of their family members. Parents talked of how a common bond of belief develops among group members:

"Because we're all in the same boat. We all have the same problem, the same hurts, the same worries, the same anxieties, I think. I find that when I go to some meetings and I hear the other women talking, I think 'I've been there too.' We all seem to have the same thing ... institutionalization. So we've all been there. We all know that horrible feeling — death, as you might say."

One mother talked of how she first heard of the parents group:

"I was so happy to know there was someone I could go and talk to ... I couldn't wait to get over there to see what this was. There was a small group there ... just knowing that you could go and talk to somebody, I tell you it took a load off my back."

A second mother described her first meeting with other parents:

"It changed my life. I don't know how I survived. The hard years all came flooding back. After I cried and talked, I felt that something came off my shoulders."

Shared Commitment to Change

Out of the sharing of experience came a commitment always to be available to help each other. This meant an end to isolation. Individuals realized others cared and would help to influence the lives of their family members. The commitments that evolved were both to personal and to social change. One woman explained how she and other members responded to the feelings of discouragement and sorrow among the group by encouraging personal change:

"When we got together, I couldn't change their child or cure their child or their situation. I couldn't move them to a rich neighbourhood or get them a job. But the people themselves, how they felt about themselves, how they thought and how they talked, those are all things that they can do themselves, and change into what they wanted. Someone said

that it is so stressful to have a handicapped child. And [someone else] said, it's not the handicap at all that's making it stressful. It's you inside, and how you're dealing with all the obstacles you have to knock down that causes stress ... and the moment you change, the stress goes."

People also expressed their commitment to change their relationship with the service "system." One person marvelled at the effect the group had as they used their collective strength to insist that they be allowed to attend planning meetings about their sons and daughters:

"We gave each other confidence to believe we should be there in the first place. And then, going was the next big step ... and you don't have to go alone, some one of us will go with you. And to this day, we go out to the institution with families. That whole aspect of families supporting each other, building confidence, never going alone, is still being carried out."

So, from these groups we learn that although each one started with feelings of isolation and futility, a change occurred towards feelings of solidarity and hope. As each person discovered that they were not alone in their feelings, that other people understood and agreed, a new sense of what might now be possible emerged. It was a process of moving from sharing sadness and pain to being galvanized into action and optimism. This process occurred in different ways in different groups. Sometimes it resulted in inner growth and maturing for members; other times in the development of new services; and still other times in an increased commitment to any group of people who were seen as devalued. Once the group began to realize that they could be mutually supportive and that they could trust each other, the process of developing goals began.

The Goals for Change

The specific goals that guided the activities of the groups emerged from a commitment to gain the power required to bring about change. These goals were directly related to the reasons the members came together in the first place and to the support they gave each other because of their common experience. The groups developed goals for mutual support among families, strengthening of personal networks around individuals, and for improved service delivery.

One group, which began as a means of support and to share experiences, soon added an educational component to some of their meetings so as to become more competent, more aware, and more able to deal with the practical realities of raising a handicapped child. Their meetings evolved to include speakers, because becoming knowledgeable and informed as parents became as important as the intimate sharing of personal concerns. The meetings alternate, one month with a speaker, one month "sharing." The speakers included therapists, school board staff, doctors, and even an income tax specialist. The other meetings started with each person saying their name and any special thing that was bothering them. The problems are put out on the floor. The group handles it. "The parents handle their own problems. They feel right about themselves."

It was this same group that, as it grew too large for the average living room, moved the meetings to a hall:

"But the atmosphere was too cold and the attendance dropped off. So we switched back to the crowded living room and, in three months, all the parents were back."

This group's goal statement, which they printed and circulated, reflected their original purpose:

"• ***to gain support from others in similar situations***
• ***to vent feelings***
• ***to discuss common problems and solutions***
• ***to learn to enjoy our children***
• ***to offer an informal social environment.***"

A second group also printed a description they had adopted from one of the other groups in this study. It runs as follows:

"***1. Every person is a unique individual, having worth no matter what his/her degree of special need.***

2. Every person has the right to a life of dignity.

3. Every person has the need for self-determination to the greatest degree possible.

4. Every person must be provided the opportunity to live as a full member of society in their own community.

Our goal: to provide a home and community life for those persons who desire an alternative to life in [an institution] and to provide similar opportunities for community residents who may be at risk of institutional placement in future."

This particular goal statement was deceptively simple. The first four points reflected the beliefs and values of the group and resulted in two distinct courses of action. One was the development of alternative community-based services as stated in the goal. These were put into place to reflect the unique characteristics, strengths, and needs of a particular person, to encourage dignity, self-determination, and choices. The second course of action was not written out, but was implicit in the four points. The group also acted to

spread their beliefs and values to others. There was a kind of "missionary zeal" whereby one group of families and friends reached out to encourage another similar group to adopt and adhere to those same beliefs.

A third example comes from a group whose goals grew out of the desire to provide mutual self-help and was described as follows:

"To develop a network of families supporting each other so that each family can grow in confidence, courage, and practical wisdom."

Whether the goal of the group was to gain power by running better services, enhancing mutual support, or by developing personal networks around individuals, the starting point was always the person with a handicap. In the past, planning for services has often taken the form of a proposal for a certain number of "beds" to be filled by a certain number of people with a specific disability. For example, a four-person group home for children with multiple handicaps, or an eight-person day program for adults with behaviourial difficulties. More recently, service planning occurs around a particular person, outlining the specific requirements and supports needed by that person.

The three groups in the study whose goals were the provision of improved services used this process of planning around the individual. Proposals for funding were submitted to meet the specific requirements of people who were named and known by the group. In addition, attempts were made to develop networks that would monitor on an ongoing basis the quality of service and the expenditure of dollars (among other things) on behalf of the person. In the other two groups, where the goal was to develop the confidence and esteem of families and friends, the service needs of each person were also addressed on an individual basis. And in all five groups, regaining control of decision-making, either to improve a service or to empower a network, was done to enhance the life of a person who was cared for and loved, not to enhance a system of services.

The above examples demonstrate that although all groups went through a process of unburdening to each other, they moved beyond that to develop goals consistent with solving at least some of the dilemmas they faced when first together. Some groups developed services; some increased and expanded their ability to help and strengthen each other and a person with a handicap; and some reached out to other groups and took the message of encouragement and hope beyond their own membership.

The Transition of Goals

The goals were not fixed and static. As groups changed, as new members joined, as certain needs were met, a transition took place: new goals grew out of the fulfilment of the first ones. These new goals reflected the growing belief of the groups that, together, they now had a new strength that could have an impact on the lives of their families and friends:

"We became a force and began to realize that people were afraid of us and we didn't know why! We recognized that we had power."

One group originally came together for fun and friendship and gradually became a political force to obtain services, to change attitudes, to educate the public. As one member said:

"I think it was our third or fourth year when all of a sudden we had a mission: improved quality of life for our children, not just recreation. Because we started realizing that we don't just recreate in life. As our kids were getting older and their needs were changing we began to realize that we needed to get involved and talk about issues! How are we going to change attitudes in this community? How are we going to stop men coming over and giving quarters to my daughter in her wheel chair? And people crying when they see [another child] having a hard time? What do you do? How not to get mad? And use oppor-

tunities like that to educate, not be angry, but sit down and talk to them. And I saw people [in the group] change from being angered by that kind of stuff to using it to show people.

When I met [the first few parents], it was not a group of people getting together because they had problems with handicapped kids. It had to do with living life, learning and growing, getting and giving support. And so what's so different from any other support group? And nobody tells anybody what to do. No. That's a big thing."

Another group that began meeting because of concerns about improving conditions in an institution developed a proposal and lobbied to have community alternatives in place. This transition was described in this way:

"We started off as [an institutional] parent support group and then, as our sons and daughters came out, obviously we were no longer the [institutional] group. But we still found that there was a need for families to come together to support each other. So it was then that the new community-based group came into being. I can remember when we first met and talked about forming the new group, but we also recognized that there would still be the need for the [institutional] group until the institution closed."

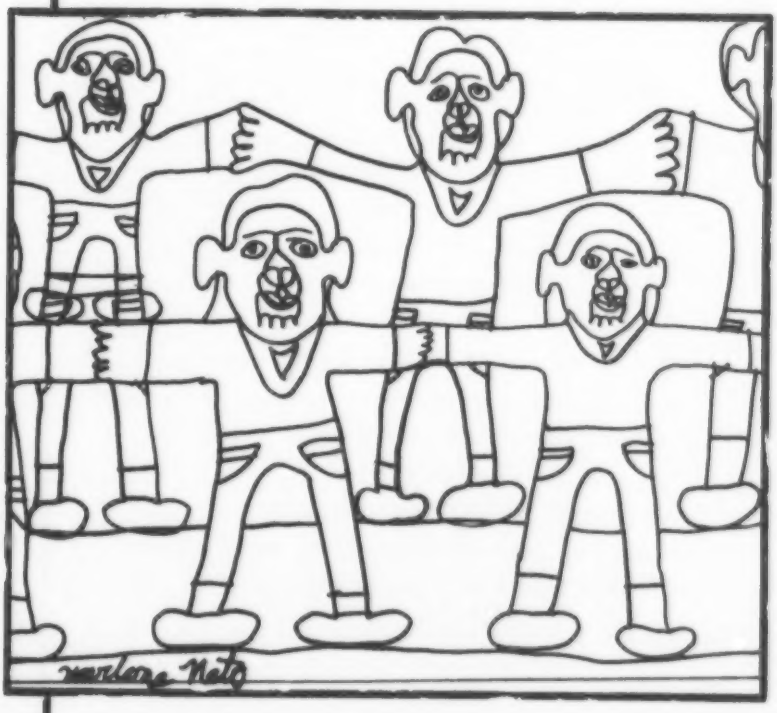
A third group began in order to have their family members remain in an institution. Over the ensuing years, and after many meetings, the families became convinced that what they wanted was "community living group homes or something in the community." At the time of the study, this group had successfully lobbied for new services, and negotiations with funders were already underway.

There was a common evolution of goals for the groups in this study. They began with specific concerns about one person — the relative or friend with a handicap. They then became involved with the concerns of other group members about their relative or friend. And finally, with growing strength, they generalized that concern to all

persons who have a handicap, or even more broadly to all people who are devalued in our communities. Another common theme was the role that support groups perceived themselves to play. Although groups developed different goals, and each went through differing transitions to create new goals, what they all had in common was a belief that they were able to be the implementors of change. In other words, the groups did not see some other agency or organization as the way to fulfill the need or reach the goal. They wanted to do it themselves — to be in the driver's seat.

BUILDING THE GROUP

"So, we had several meetings
together in our homes.
It didn't take us long, though,
to realize that there were
an awful lot of families out there
that we have got to tap into and keep informed.
I don't think we had many more meetings
before we determined that we needed a little bit of structure.
But it sure wasn't formal
because we weren't looking for [status].
We were just looking for a mechanism to do something,
and in order to do it, this may be what we need."



Having a shared commitment and goals for change is not enough to make change happen. Groups need some form of organization for their empowerment — membership, a structure, leadership, and some ways for managing conflicts. In this chapter, the groups share their approaches to these four building blocks of development.

Membership

Membership began because of a sharing of common experiences and a commitment to help each other. In some instances even the first meeting of the group had a profound effect on creating shared commitment.

"So what we did for each other was sort of promise that we'd never be alone and we committed each other to be there at the end of a phone or at a meeting. And I think for some of us it became the driving force in our lives. The need to be in touch with each other, to share, to dream something different."

The members of all of the support groups in this study were brothers and sisters, parents and grandparents, aunts and uncles, friends and guardians. For these people, as with other families and friends, there is little else in life that is more important than helping someone whom they loved to lead a full and enriched life. So, when a group of people got together with this kind of purpose, it was bound to affect them in a personal and profound way. All of the groups had members who had taken on the work of the group as a way to fulfil a personal goal. One advocate suggested that it was her way of giving something back to a society that had treated her well. Another woman said that the many hours of work she put in were as restoring as play. And in several of the groups, the members referred to each other as "family." One mother explained in more detail how the group offered her this kind of membership:

"I know that if something were to happen to me or to [my husband] or to both of us, the families that I leave behind ... will always be there. I know my two sons will always be there and they'll have support and they'll know that they can come to the group and they can talk to them ... To me it's a family. They are like my family. So I would never give it up. Never!"

The voluntary nature of the groups caused the bulk of the work to fall on the shoulders of those members who could find the time and who had the skills to take on the responsibility of the work of the group. The countless number of hours needed soon weeded out those whose time was limited. For those who were able to be available, the purpose of the group must have been seen as having a personal and particular importance to maintain that level of voluntarism. In one of the groups a woman put it this way:

"It was difficult. It was hard work for all of us. And where I was, my work ... Thank God, I could free up the time to do all the things I needed to do. I don't think a parent could have done it [alone], nor me if I'd been working somewhere else. I had my job, my two kids, the volunteer work at the camp, my other volunteer work, and someone said to me, 'My gosh! When do you get to play?' And I said, 'This is play for me.' I get so much energy from this. What is work for someone is play for others."

In another group, one of the leaders said:

"If, in the early days, you had told us that it would take this long to achieve the vision, we would have all gone home! Thank God, nobody told us! I'm glad I didn't know it would be such a struggle."

And a third member commented:

"It's incredible when you look back and see what a small group of people have done and what they have put in place."

Because of the time involved, and the personal struggles, the active involvement of members was a fragile thing. But the fragility of the group was also its strength. It meant that every member counted. It meant that strength did not lie in the number of participants, but in the ability of the group to maintain the commitment to each member — the commitment to support people when they needed it, and to respect the choices that people made. To have membership had little to do with having a vote. It had to do with having support and being included. One woman spoke of how being a member meant she had someone to stand by her:

"Since I became associated with [the parent group], they're always there. Even if I don't see them for a while, I know that if I'm desperate or I want support, all I have to do is pick up the phone and I get it. Even with other societies, I've never found anything like this. They are a special kind of people. They have their values straight. They do encourage you. I can't change the past, but I can change the future. If you're still living, you can change the future. It only takes one person to change."

Internal Structure

The structure of the support groups in this study was directly related to their goals. The decision as to how formal the structure should be was influenced by what the groups saw as being a practical and useful way to use their influence, by what the specific goals were, and by the size and composition of the group. For example, some groups decided that the best use of their power was in providing and monitoring an improved service for their friends and family. And so a formal hierachy was required to receive funding, hire staff, and so on. In this way, these groups were following the path travelled decades ago by the people who began local Associations for Community Living.

For other groups, the goal was to maintain equality and an atmosphere of mutual support. Therefore, a formal structure was seen as getting in the way of their reason for existence. A formal structure would create a hierarchy of board and committee members, on the one hand, and the general membership on the other. This was seen as conferring special status on some members, possibly at the expense of others. And, since they were not focusing on service provision, there was no demand from funders to develop a hierarchy of management. One of the less formal groups described the difference:

"We have a real routine at meetings, but no president, no secretary, or boards. Not anything like business meetings. There are no heads, no bosses. The group decides, the majority wins. We each give money for coffee, and someone takes it over, but that person is not the Treasurer!"

A second group had written material that described the structure of their group as:

"an informal, non-profit organization of parents and family members of individuals with mental handicaps. We are not a sophisticated group. We are ordinary people who have suffered the hurts and frustrations of dealing with the 'systems' surrounding our family member with a handicap. We are not a professional service agency, not a group of expert problem solvers, and not another bureaucratic or administrative machine."

Another group used their large, province-wide network. The "grapevine" kept the leaders and members informed of who needed help, where, and how. This strong but informal network allowed the leaders to "float in and out as needed."

All of the groups in this study had a common desire, namely, to gain power to improve the quality of life for their family member with a handicap. But there was a significant difference between the groups as to what actually constituted power for positive change. If the group believed that the way to gain that power was by controlling services, then a formal organization was required. If power was to be gained by developing a strong, vocal, and competent network around the person with a handicap, then the personal and intimate support of a self-help group was needed. If power was to be achieved through families and friends developing their own personal strength and commitment, then an organization that remained informal, always ready to listen and provide support, was the key. As a result, the groups adopted different internal structures according to their own understanding of what would best provide an improved quality of life for friends and family.

Leadership and Direction

The groups' leadership has tended to come from families and friends. They have evolved two types of leadership. In the first, direction was formally vested in a board. Members looked to one person or a small core of people to provide guidance, solve problems, and plan the future direction of the group. With the second type, direction was unstructured, subtle, and rotated among the members. They looked to themselves and each other to provide guidance and planning.

The particular type of leadership style chosen by each group depended, for one thing, on the goals they had set for themselves. For example, when the goals included the provision of services, the first type of leadership was required because an incorporated board of directors with officers and committees was necessary to be eligible for funding. Two groups developed along these lines. A third group did as well, but since the services they provided were for a limited time, the authority vested in the board was only temporary.

In the other two groups, the second type of leadership was chosen. Since they were not focusing on service provision, there was no demand from funders to develop a hierarchy of management, and no desire on the part of members to have a board and officers. These groups believed that the development of different status for different members would interfere with the equality and importance of each member. They also felt that each member was a potential leader, that each person had talent in one area or another and, as the work of the group required that talent, each person would take a leadership role.

Common to all groups was the strong belief that the group could solve its own problems, find its own answers, look after itself. It was as if the autonomy and self-respect that the group wanted for their family members with a handicap was also wanted for the members themselves. One member said, in reference to the leadership required for this kind of group, that:

"The real leadership will always come from people with a handicap. [Our group] will always need rebels with common sense who can be militant and who can take direction from people with a handicap and their families."

The leadership that members wanted from themselves and from outside resources were people who would enable, facilitate, empower, and assist the work of the group. What they rejected were people who would direct, instruct, or take over the group. This attitude held for people whether they were professionals, other parents, or those who rose to leadership positions within the group itself. One leader explained her experience in these terms:

"in the early days of meeting, my ego caused me to think I was responsible. But now I hand the problems back to the group. This was a big thing to learn."

Another woman recognized early on the type of leadership required:

"at our very first meeting, a lot of people leaned towards me because I was the one who was leading, but I recognized the danger of becoming that solid post — and there was no way I was going to do that. Someone else had to do it, take on the leadership role. And the leadership role I played was to support the leader I could see in the group."

She went on to describe her own definition of enabling or empowering:

"I wanted them to learn, I wanted them to do it all by themselves, I wanted them to be 'able.' I was the one who went through the door first. I can't be going through doors all the time, because what happens is I go through the door and sometimes run way ahead of you guys, and when I look back, there's another door that's being built, and you guys don't know how to get through it. So I had to teach them how to go through it."

One advocate interviewed said that "the group learns by process not direction." So, neither those in a leadership role nor the members themselves were expected to have all the answers, but to assist and support each other in finding their own answers. Since most of the groups formed initially around a strong leader or two, this process of strengthening the skills and confidence of the membership provided a balance, and also went some way to ensure that, if the strong leader was not present or active, the group would be able to continue without him or her.

The most effective group leaders were the ones who saw themselves as having knowledge and skills that could be shared with the group, rather than used to direct the group. While certain members were seen as having more leadership skills than others, the strengths and abilities of all members were respected and called upon. This was especially true where the goal of the group was personal support and it was least true where service provision was the goal. The demands placed on the groups who operate services tended to mitigate against an informal, rotating leadership, to require a reliance on professional skill and a necessity for accountability to several different bodies. The groups whose goal was to provide personal support did not have those demands. They were able to remain focused on supporting friends and family of a person with a handicap. Their energies were spent helping each other gain the knowledge and confidence to act on behalf of that person; not on developing and maintaining hierarchies of management.

Conflict Resolution

Given that groups placed an emphasis on people being able to find their own answers and make their own decisions, the question arose as to how conflict would be resolved when members disagreed about goals and strategies. The groups in this study dealt with the conflict in several ways. In most instances, it was important to the groups that the disagreement not lead to rejection, and

that compassion was a better tool than confrontation. One group, for example, wanted to press charges and go to court on behalf of their family members. This action took too hard a line for one mother who decided to withdraw from the group. The group understood and said her decision was perfectly all right. Later, when the mother felt she could, she returned to attend the group meetings, and that was alright, too.

One group member told of how she felt some of the group were depending on the leaders to make all the decisions and then were resentful when those decisions were made:

"One thing that really gets my nanny. We'd all be at a meeting and then they'd jump on her [one of the leaders] saying, 'You shouldn't do this, you shouldn't do that.' And I said, 'Hey! What's the matter with you? Why are you there? Why aren't you here, deciding?' One time I got so angry I said, 'You people remind me of when I was on the farm and I went to get the cattle.' They'd wait until I'd opened the gate before they'd join. Why don't you open the gate yourself?...get these things rolling?...Why wait?"

One of the biggest challenges for groups was the support that families needed when a family member was to leave an institution. The challenge was in dealing with the pain and conflict that inevitably arose, while respecting people's own experience, opinions, and choices. One mother described how unsure she was regarding community living the group was recommending for her son:

"I needed an awful lot of help and that came from the other families. When it comes to the life of someone that you really love you want to make sure that what you are doing is really in their best interest. But a lot of things that I thought were in [my son's] best interest, maybe weren't. I was the one that was being over protective. I was very, very afraid. And I know that it couldn't have happened as it did without the families surrounding and saying it's not going to be that bad. Again, it's because they had gone through it that they could say what happened for them and how they handled it."

Another mother looked at the same problem but from the perspective of the members of the group when they encouraged community living:

"Because I had help from other families, I was in a position to say to others what I had been told myself. So that's where the ripple effect comes in. I guess that's what we, as families, do. You can support families to the degree that they are comfortable and then you have to back off. You let them know that you are always there, if they want to take the next step, to help them. That's where I see [the parent group] helping ... and grieving for them, the families that are too frightened to rock the boat."

And when there was major disagreement over what the best course was, here is how one parent described her experience:

"As soon as we started to talk about some of the risks [of community living], this caused some families to step back a bit. Some families were tired and some couldn't see the alternative, so they stepped back. A lot of us struggled with them because they were our friends by now. It became very difficult in a meeting when someone you'd been supporting and sharing personal things with is hanging back from you all of a sudden, not supporting your goal, whatever that happens to be. You start to feel uncomfortable. You go to meetings with a knot in your stomach. So then it's not so much that we have to [support each other]. There's a much larger issue. There's this goal [community living] ... What do we do with those who don't want to take the next step? We all had to go through the process of determining what we did. I had to leave them behind. I didn't reject them in any way, but I left them behind to get on with the goal for my child."

A member of the same group talked about her initial reaction to the idea of community living for her daughter:

"At first, I was very apprehensive, I must say that. I was afraid like a lot of people are still to this day. I wanted her out of [the institution] but I didn't think the community would accept her. Because they didn't before, why should they now?"

In trying to resolve the polarizing arguments about whether people should live in an institution or in the community, one group decided that they were not able to support their members who wanted to fight to keep the institution open:

"Because of our belief, we couldn't support them in their fight for an institution. But we can say it's your right if you want to, but we're always here to show you some alternatives."

And from another group:

"One couple has stopped coming. Some people wanted to write to them to get them back. I said 'no.' All we can do is let them do what they want. They know that we're with them and still supportive. Our purpose is to support. Don't push."

But not all disagreements ended in parting. One woman described how the members stood by her as she struggled:

"The group grew. Sometimes we'd get sixty to seventy people at a meeting. And when they heard what it was all about, some were afraid and would step back again. And maybe a month or two later they'd come back and listen some more. See, they were trying to make up their mind like me, only I kept going ... I never missed a meeting because I knew they were on the right track, but I was afraid. There were a lot of things that I would argue about. But they would hold your hand and they wouldn't let go. Even when you get frustrated with them, they never once let go of your hand. They took me through a big time in my life. I was desperately afraid for [my daughter]."

When faced with internal conflict, the groups tried to mend the rift. They first returned to and affirmed their initial reason for coming together. This often helped to focus the group towards trying to figure out why they were in conflict and away from being diverted with arguing. It also reminded everyone that mutual support was still central and important and reaffirmed their common concerns.

And when new goals replaced the initial ones, sometimes the history had to be retraced, reminding the members why they were now dealing with difficult issues and not just listening to each other's stories.

On the one hand, the groups understood the need to remain united and cohesive. This was important not only because they would be more powerful, but also because the members had shared deeply and cared about each other. On the other hand, the groups respected the decisions of the members. If the conflict situation developed into one of clear incompatibility, then the action they took was to respect the choices of those who disagreed and to move on with the others who still saw themselves joined to a common purpose. The process was painful for everyone. But, it was felt, a greater loss would have occurred if the group got caught up in internal strife and became vulnerable to the "divide and conquer" stance of outside power sources.

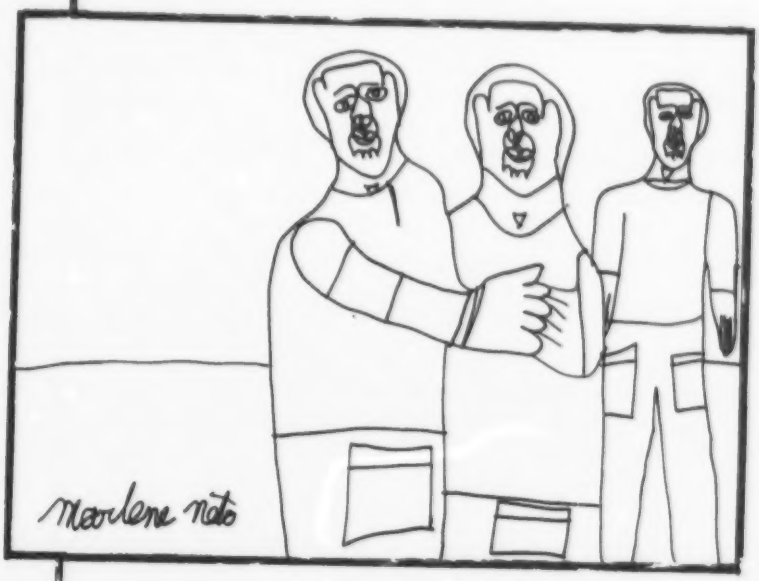
Of particular importance in the resolution of conflict was the keen awareness that fear was often expressed in anger or in tears. When rage and sorrow were peeled back, the real problem was often panic. Each member had experienced that, so each member was a potential resource to the other in helping to move beyond fear to trust. Few things were felt to be as effective as having someone say: "I know how you feel. I've been there and I'll help you through."

This is not to say that the groups did not lose members. Some people left, to return later when able, others stayed and argued repeatedly until trust was regained, still others split themselves off to form new groups, unable to remain a part of the old.

All the groups demonstrated that dealing with conflict could be resolved with respect and dignity by reaffirming goals, retracing history, respecting differences, and offering to allay each other's fears.

MANAGING OUTSIDE RESOURCES

"Through my own experience,
I feel you need to be [with families] first as a listener.
Some don't want any instruction
or else are not ready to take that step.
We have enough professionals telling us what to do.
We don't need more people stirring the broth."



Because of their personal experiences most groups harboured a mistrust of the very services and agencies that were developed to serve them. In this chapter we look first at how groups experienced the limits of support from outside resources, in other words, the lack of "understanding" from services and agencies. Second, the groups' strategies for "interdependence" are identified: strategies that allow them to use resources without undermining their autonomy.

The Limits of Support

For the most part, the groups recognized that many individuals working in human services were trustworthy and could be called upon to be valuable resources. On the other hand, many service workers were able to offer help only if certain criteria were met and this resulted in the families and friends feeling rejected, alone and, once again, having no control. This is a common dilemma. The rules of the various organizations providing funds or services frequently tie the hands of people who came to work in the area of human services out of a desire to help. Caught in a conflict of interest, even a caring professional must do what is seen to be best for the organization often at the expense of what is best for the individual needing service. As one mother said with some candour:

"I had worked for years for my local association always hoping that [my son] would benefit, but knowing in my heart of hearts that he wouldn't benefit because he didn't fit the criteria."

Another mother told how her daughter was ineligible for a place in a group home because she was not toilet trained and was unable to dress herself. In most instances, the sons and daughters who did not meet criteria did not get served or else they were institutionalized as an anguished last resort. And once that step was taken, the important decisions — for example, where a person lived, what money was spent to provide support, when visitors could come —

were all made without including the person or the person's network in the planning process.

In the experience of these groups, it was not only service providers who could not support the interests and demands of the parents. To add to their problem, many local associations perceived the new parent groups as a threat, potentially fragmenting or splintering the "national parents' movement." All the groups had experienced this lack of support from local service providers, from funding bodies, and from other parent-to-parent groups. And as individual families they experienced lack of support in their own neighbourhoods and communities. One mother explained that she had four years of experiencing her son as a "normal child" before he was diagnosed as having a handicap. Once that happened, her family was seen by the neighbours as "the handicapped family."

"I experienced what I've heard a lot of parents talk about. You're set apart ... you can't do this and you can't do that. And it's not that you can't do it. But it's understood that you can't."

Some members, because of these experiences, were easily able to identify those professionals or parents who would help by "giving over" the resources to reach the group's goals. Others, because of these experiences, felt that no one who had not gone through what they had gone through could be trusted. Both attitudes were present in all groups. In some situations, even the existing parent groups were not seen as providing the kind of vehicle these families needed at that time. For example, one woman contacted her provincial organization and was invited to a meeting. Her expectations were for a different kind of meeting than the one she found: "it was a business meeting, for Heaven's sake, not at all what I was looking for. No support."

It was this loss of support and influence that saddened, angered, and frightened the members of the groups and made them wary of anyone: professionals, neighbours, and even parents who used

their knowledge or position to dictate how life should be for the person with a handicap. These limits of support led to the belief that one way to avoid that feeling of powerlessness was to keep the group independent, autonomous, and guided from within so as to protect their vision for their family members who had a handicap:

"We felt that an independent, non-aligned organization was needed whose objective was to support families to get what they needed."

Toward Interdependence

For the groups in this study, although "autonomy" was essential, it did not mean the severing of relationships with outside resources. Members talked of many different occasions when the support obtained from associations and other organizations was positive and welcomed. Four kinds of support from outside resources were identified: (1) involvement of professionals; (2) support for lobbying; (3) consultation services from agencies and associations; and (4) recognition by service providers of the value of co-participation of the families and friends.

(1) Involvement of Professionals

In some of the groups, professional human service workers, who were not family or friends of a person with a handicap, were members. Their role was as an auxiliary to the parent leaders. They embraced the values and beliefs of the group and respected the members of the network as decision makers. They were able to accept that the group learned from its own actions and decisions and not from being instructed by "someone who knew better." They understood that the whole is better than any one of its parts, even if one part was "an expert." In particular, they provided knowledge and information to the group so that decisions were made with a full understanding of all possible choices.

Professionals also accepted the fact that they could not really understand the past sorrows and frustrations that the families ex-

perienced. Families and friends had a fuller and more intimate knowledge of the person with a handicap. The professionals involved in supportive roles saw these experiences as giving the members of the network an equal and complementary "expertise" to their own. This attitude of equality was sometimes difficult to maintain. One woman explained she had struggled with her role in the group because, although she identified strongly with the parents, she herself was not the parent of a child with a handicap. So, at a certain level, she felt she was not really a part of the group. This dilemma was overcome when she was told that her role was similar to that of "a white civil rights worker." She had a much needed and complementary role in the group, not the role of a parent, but the role of a partner. The rewards for professionals, then, came from being part of the group's growth and action and from sharing in the feelings of solidarity and valuing that go with membership.

(2) Support for Lobbying

Some groups had also obtained resources for their lobbying efforts from provincial and national Associations for Community Living. One group was offered the support of the Canadian Association for Community Living at its national annual conference to act as a catalyst in bringing pressure on government personnel to respond positively to their requests. Another leader stated that her provincial association has been very supportive of the group and its proposals. One provincial staff member in particular "has been 100 percent supportive." In two provinces, it was either the provincial or the local association that suggested which groups should be studied. In both cases, the association had been actively involved and the staff knew how to provide assistance without trying to direct the group. They helped the group attain its own agenda.

It is critical to recognize that, as far as the support groups are concerned, the respective roles played by the associations and the groups themselves are quite different. For example, one member said that the personal support group was like her family while the local and provincial associations played a "corporate advocacy"

role. So, in her view, there was no need to be threatened or competitive. The established associations could call on the personal support group to swell their lobbying ranks. And the personal support groups could feed important issues to the associations for city or province-wide action.

(3) Consultation

For support groups in their early stages of development, the more established parent groups, and sometimes the service agencies, can play an important consultation role. At the time of this research, one of the groups being studied was in the midst of helping another group of families to form their own board and start providing services. This was finally accomplished by using an outside and established service agency. This agency received funds, hired staff, provided meeting space, and offered other resources as needed. Once the families developed their own incorporated board, the sponsoring agency spun the services off to the new board to run the services directly.

(4) Recognition from the Service System

The need to move toward interdependence, while maintaining autonomy, was also reflected in the fact that families had to continue to use the service system to meet the needs of their family. The question was how to gain recognition from these systems of the rightful place for families within it. The support group played a pivotal role in changing the terms of the relationship between family and service provider to empower the individual and the family. In one example, a mother's trust in the service provider was renewed when she was able to regain an influence in the life of her son:

"First of all, I had to be part of [the support] group and absorb their philosophy. And as I got comfortable with what they were doing, [I could] say to them that I really wanted my son out. I had never wanted

him in there in the first place! So again, it was a process of feeling comfortable with it. And I also had to feel comfortable with the [service provider]. As I started becoming more involved as a volunteer, I could see the control was coming back closer to the parents and that was a turning point for me."

Another mother described how she coped with a potentially adversarial situation at a meeting by taking another parent along with her:

"You really can't describe what it means to a family, supporting you in what you believe in. When all your life you've been told it can't happen because...! You knew it was going to be an uphill battle because that whole group of people was looking at you as if you were out of your mind. And suddenly, you felt you knew that you weren't."

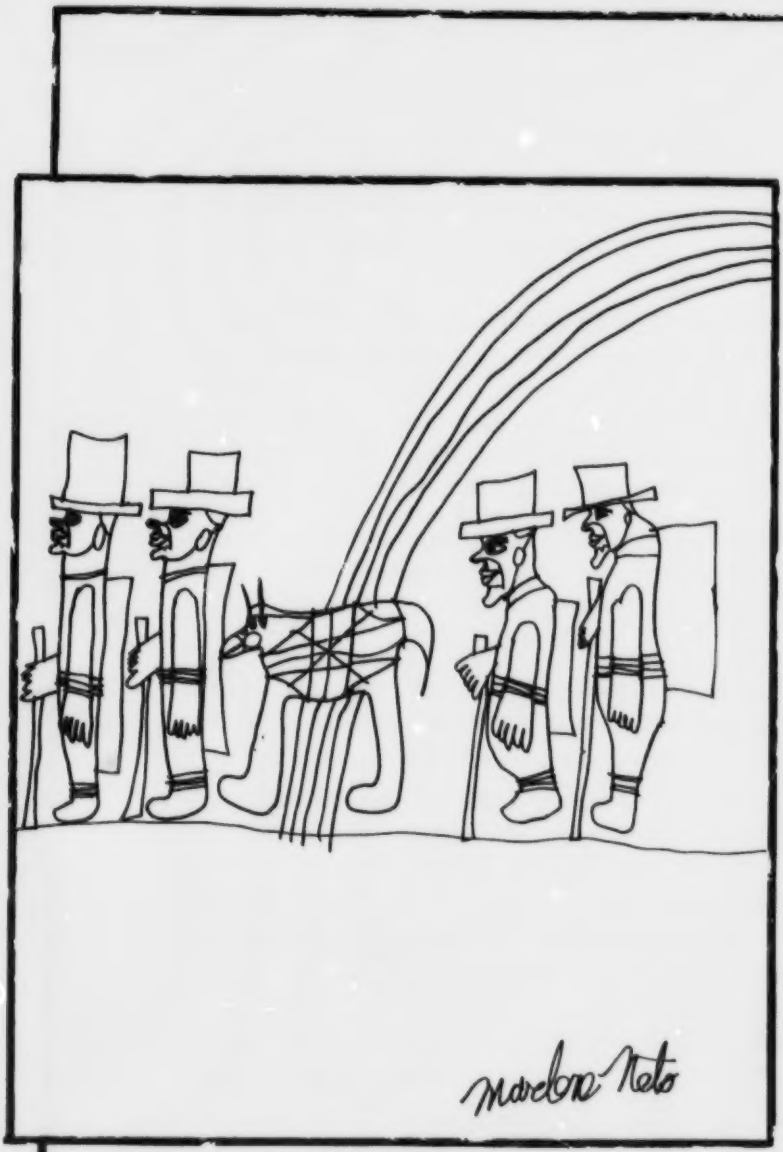
Since these groups formed, at least in part, because of a dissatisfaction with existing resources, it was understandable that a tension would continue to be present until the members, either collectively or individually, experienced some degree of recognition, acceptance, and respect from those resources. The feeling of having been "rendered powerless" by the very organizations that were designed to help died hard. But it did die when it was replaced with an understanding that the family and the personal network could be heard and have influence.

The pivotal point in the groups' relationship to other resources is power. Once the power shifted from being totally outside a group of families to being shared with the group, the relationship shifted as well. The tension was still there, but there was more harmony than discord, more cooperation than competition.

Of particular interest was the relationship between the established associations and the independent groups. It was generally agreed that the local and provincial Associations for Community Living could be a major source of support. One woman gave me several examples of how such support could be given.

- Invite families and friends from the community to meet with members of the independent groups. Then, encourage and nurture their learning to be mutually supportive by letting the group discover its own agenda, set its own goals, and develop its own cohesiveness.
- Support the independent groups as they petition the government for changes and improvements. This assistance can be useful to both parties, even when the association is receiving government funding and is caught in a conflict of interest. An independent group can be in a better position to push openly for changes that, in turn, would benefit the association.
- Recognize the value of the independent group with its focus on the individual. This provides a needed balance to the service-providing association that must concentrate on supporting staff, budgeting funds, and managing an organization.
- Make the resources of the association available to the independent group: a place to meet, a desk with a telephone, secretarial support, photocopying and mailing privileges, as examples.

These examples of support assume that the associations see themselves more as a catalyst than a controller. They are prepared to be the vehicle through which support to families and friends is shared with groups operating outside the associations. They see these new groups as members of the same team — not as a threat. They are, in fact, open to sharing power.


Marcelo Neto

CONCLUSION: ORGANIZING FOR EMPOWERMENT

"For me the dream is for families
to have a common voice,
an effective voice,
to have the support of each other,
to have it right across Canada,
in each community,
and not to have to depend on one central place to coordinate it,
but to have that capacity to coordinate their
own community of families supporting each other."

This has been a study of how families come together to empower themselves. It is about the support they provide each other to face the limits that have been imposed on them. It is also about how they organize to cross these limits.

This chapter summarizes the process of "organizing for empowerment." It is a process that can be seen in the experience of many support groups across Canada, some of whom have shared their stories and perspectives for the study. Although each group finds its own path, their collective experience suggests six stages in the process of empowerment.

Autonomy: The group often finds its strength in a perception of its own autonomy. For people who have had so many decisions taken away from them they need a place where they can begin to regain some control in their lives, and be supported in doing so. The group must be free to reach its own goals and develop new ones, assisted by funds or other resources, but not directed by them. Autonomy is the first step towards establishing the group as a unique entity, having its own special identity and purpose, able to discover and develop its own power.

Security and Support: The group provides its members with a sense of security and support not obtainable anywhere else. This mutual understanding and communality of spirit allows the group to move beyond the sharing of experiences with each other to taking action. Strategies for action come after people recognize and validate each others' needs, understand the commonality of their experiences and, through that, give each other the strength to make a commitment to bring about change.

Vision: From the strength that comes from mutual support and shared values, the groups develop a vision of how life could be better and fuller for those with a handicap. Each group's vision is developed in response to the needs brought by families and friends. This vision allows for the development and then the transition of goals. It is not static. It needs to be developed and redeveloped, affirmed and reaffirmed as the groups face struggles and conflicts.

Action: Groups often reach a stage where they want to take action, to exercise their power. The group seeks to have an impact on systems, and on people other than its members, to change the conditions that give rise to their needs. In so doing, the group discovers its own strength. As the group reaches out to change or develop services, to build links with other parts of the province or country, it takes its vision beyond its own membership to influence and assist those concerned about a person with a handicap.

Leadership: Central to the concept of empowerment is leadership that facilitates and assists the groups to grow and develop but that is not directive or controlling. So, it follows that decisions are made or problems are solved within and by the group, through consensus or majority rule, for example, not by board policy or dictum. It also follows that the "sense" of being the leader is shared, since it is recognized that each member has talent in one area or another. As the work of the group requires that talent, each member has the opportunity to exercise leadership within the group. As a result, everyone is needed and valued. An empowering leader strengthens the skills of the members, instills confidence, and nurtures the sharing of power among the members first, so that it can then be shared with the person with a handicap.

Interdependence: Autonomy is one side of empowerment; interdependence is the other. Support groups need a protected place to begin their growth. As they begin to develop a common vision, goals, and strategies for action, they sometimes need to call on other resources outside their own. A re-alignment of power toward people with handicaps and their families is an essential condition of interdependence. A re-alignment of power occurs when people with handicaps, and their support groups, set the terms of their relationship with outside resources — whether with associations for community living, service agencies, or the broader funding and service system. Interdependence is achieved when these outside resources respond in kind.

On reviewing the work of each group, we can see how in each case it reflects the group's understanding of what would be "an improved quality of life." In two of the groups, a better life meant moving from an institution, or from a family home, to one's own home. Thus, they organized to establish and influence community living support services. In both instances, those moves have occurred. Residential and other services, which did not exist prior to the formation of these groups, do exist now for the specific people around whom the group gathered.

As well, because of their success, families and friends of other people with a handicap are approaching these two groups for assistance and inspiration.

One group continued to take an advocacy stance for people with a handicap. Because of their independence from established associations and from funders, they are able to make demands for improved services or more individualized attention, either directly with the person with a handicap or indirectly by supporting the family and friends.

This group is able to cross all boundaries, petitioning both the bureaucratic and the political leadership, making demands on health, education, and other services because they owe allegiance only to their own membership.

This particular group has also been instrumental in establishing two additional and new services started by two other new groups of families and friends. The experienced members of the group provided resources to the two new groups so that they were able to develop community living services for their family members who were institutionalized. Together, the groups have recently opened two new homes, with two more scheduled for the future.

One group has remained committed to the personal growth of its members so that they may be stronger and more confident as they advocate on behalf of the person with a handicap.

One of the leaders told me that over the past year she has taken a new job and was less able to be active in her group. The group continued its work — for example, introducing a family whose child was very seriously ill to another family who had been through that experience. She, for her part, was able to link new families she met through her work, with the original group.

Where gaining self-confidence to advocate was the issue, she organized visits between the new families and the original group to allow the process of sharing their experiences to be pertinent and first hand.

Through her, the group learned of other families and friends who were interested in similar issues — integrated education, for example — and thus joined forces beyond their own community. The group is currently developing an informal partnership with a group in another town to find alternatives to sheltered work as an option for people who have left school.

The fifth group also remains involved in providing family-to-family support. They have had a change in leadership over the past year and have used the time to make new plans for outreach to other families. The links between families are more informal and spontaneous now, whereas earlier they were more planned and orchestrated by the leaders. This group is beginning to investigate the possibility of obtaining funding in order to provide on going staff support to the work of the family support group.

Throughout the course of this study, several support group members spoke of a "rebirth," of a renaissance of the force that began the parent movement in Canada decades ago. And they spoke of "getting back to the roots" of this movement. This study suggests that the roots of the movement, and the source of its renaissance, lie in the process of empowerment.

Many parents and friends of people with handicaps provided a guide to this process as they talked of their experiences in interviews for this study. Through their experience we come to understand that empowerment begins with the opportunity for people to put prior, painful experiences into a new context. As they share those experiences with others, and receive validation and understanding from each other, they gain mutual respect and strength. Empowerment also comes through a particular way of enabling or facilitating. It is a process of passing power to another person, of leading by encouragement, not instruction. It is reflected in the understanding that the strength of the group is in its solidarity and not in the knowledge and skills of those who have more expertise. This is not to demean knowledge and skills of others but to say that the knowledge and skills of families has been denied for too long.

Support groups have found themselves able to take action, to become empowered, because they have found great strength in joining together around a common purpose. Their common purpose is to improve the conditions of life for people who have a handicap. This is also the purpose of associations, service providers, and funders. The collective challenge is for each to recognize the importance of the other, to acknowledge their interdependence, and by so doing, to redesign the distribution of power to ensure that people with handicaps are included as full and participating members in society. As one parent said,

"We want community living for everyone in Canada ... Isn't that the dream?"

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Righting Wrongs: ***Disability, your Ombudsman and You***
1989

The Pursuit of Leisure: ***Enriching the Lives of people with a Disability***
(revised edition) 1989

Leisure Connections: ***Helping People with a Disability Lead Richer Lives in the Community***
1989

Family Support Services: ***An Annotated Bibliography***
1989

The Language of Pain: ***Perspectives on Behaviour Management***
1988

Income Insecurity: ***The Disability Income System in Canada***
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Keith Edward's Different Day
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Vulnerable: ***Sexual Abuse and People with a Mental Handicap***
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Service Brokerage: ***Individual Empowerment and Social Service Accountability***

1987

Community Living 2000: ***(Canadian Association for Community Living)***

1987

The Family Book: ***For parents who have learned that their child has a mental handicap***

1986

entourage is a quarterly, bilingual magazine that looks at how people with a mental handicap can be supported by the community to live, learn, work and enjoy life. It includes current information, features, and artwork on issues related to the lives of individuals with a mental handicap.

All Institute publications are available in English and in French. For a catalogue or for information about these books please call:

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The G. Allan Roeher Institute

Canada's National Institute for the Study of Public Policy Affecting Persons with an Intellectual Impairment

The G. Allan Roeher Institute has two major goals:

- to identify and anticipate future trends that will support the presence, participation, self-determination and contribution of persons with an intellectual impairment in their communities;
- to foster the exchange of ideas leading to new ways of thinking about persons with an intellectual impairment.

The Institute conducts, sponsors, and publishes research in a wide range of areas, with a major focus on public policy and funding, on studies of innovative social programs and on the development of policy alternatives. It offers training programs and workshops across Canada on topics such as integrated education, post secondary education, leisure, employment, and alternatives to intrusive methods of behaviour modification. Through its Information Services, which include a library, a book and film distribution service, and a computer-accessible information system, The Institute provides up-to-date information to the public, professionals, and community groups. The Institute also publishes the quarterly magazine **entourage.**

The G. Allan Roeher Institute is sponsored by the Canadian Association for Community Living, a voluntary organization bringing together over 400 local and twelve provincial and territorial associations working on behalf of persons with an intellectual impairment.

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